Thespena Panos

Lymphangioleiomyomatosis (LAM)

For seven years, I knew something was wrong. I had a hard time breathing and started coughing up blood clots with exertion or exercise. I went to several pulmonologists, but no one could find anything. On a family trip to Greece in 2014, I had a severe episode while swimming. I couldn't breathe, I became dizzy and almost passed out. I spent two days in bed unable to move. The doctor thought it was an asthma attack and gave me an inhaler. When I came back home, I had a CT scan, and everything seemed normal. I saw another pulmonologist who told me there was nothing wrong, and that I just had to lose weight. With despair, I tried to explain that I had had these issues even when my weight was normal. How could I exercise when I couldn't breathe and kept coughing up blood clots? I distinctly remember him saying, "I don't know what to tell you...just lose weight." I left heartbroken and ashamed.

Deep down I knew this was more than a weight issue, but after a couple of weeks of being down on myself, I decided to get a personal trainer. During my initial assessment, I could only climb a step for about a minute before having to sit down gasping for air. The oximeter showed my oxygen level was 82. I sat until my breathing returned to normal and the oximeter showed 98. The trainer thought the oximeter was broken, but I knew something was severely wrong. I bought my own oximeter, monitored myself and kept a detailed log of all my mysterious health issues.

It wasn't until late 2016 when an internal medicine doctor, a good friend of mine, truly listened to my cries for help. I went to see him for what I thought was a bad bout of bronchitis. After an extensive conversation, he walked out of the exam room, passed a room with a pregnant woman waiting to see him, and suddenly remembered reading a question about LAM the year before when he took his recertification exam. He admitted me to the hospital the following week for tests, and a CT scan showed I had hundreds of cysts in my lungs. Turns out, there had been cysts on my 2014 scan, but they were missed. I was sent down for a bronchoscopy and the procedure went terribly wrong. I ended up on a ventilator.

The first thing I read was that life expectancy was 8-10 years. I was devastated at the thought that I may only have a year or two left, especially being a single mother to my two beautiful daughters on my own, Sophia and Eva. Until I knew more details, I decided to hold off telling them the name of the disease because they would have immediately turned to the internet. Despite my fears, my first job was still to protect my daughters and make sure they were living their best lives.

I learned about the LAM Foundation and called them for support. They gave me a wealth of information, resources, clinical trials and treatment options, and the latest medical research. They also referred me to the closest LAM clinic in a nearby state. However, my insurance wouldn't allow me to cross state lines to see the LAM specialist.

After continually getting denied, I contacted my congressman to help me fight the state's department of insurance to allow me to be seen at the out-of-state medical center that could provide me with effective treatment. After four months of appeals, I finally was approved for a bronchoscopy, but it ended up being inconclusive, so the next step was an open lung biopsy. In May 2017, it was FINALLY confirmed that I have lymphangioleiomyomatosis, LAM.

I was put on a drug that was approved by the FDA to treat LAM just seven years ago and is helping women live longer than 8-10 years with a better quality of life. Unfortunately, LAM has already destroyed my lungs to a point where I will continue to need supplemental oxygen most of the time, for the rest of my life.

The hardest part for me is knowing that if I had been diagnosed sooner, I would not require oxygen today. It took me a few years, but I can finally talk about my diagnosis without crying. I went from deep despair to renewed hope and a determination to live life to the fullest. I am truly blessed to have my family and friends by my side, especially my daughters, my fiancé, and my parents. They've been my rock, my strength, my hope...and I am so grateful for all their love and encouragement. This meandering journey of misdiagnosis or delayed diagnosis MUST stop. We need new therapies and greater awareness about LAM. We need to find a cure!

Lymphangioleiomyomatosis (LAM)

Lymphangioleiomyomatosis, also known as LAM, is a rare lung disease that mainly affects women, usually during their childbearing years. LAM is caused by mutations in the tuberous sclerosis complex (TSC) genes. These mutations lead to growth of abnormal cells that spread by the blood stream and make their way into the lungs. Once in the lungs, these cells create holes in the lung tissue (called cysts) that can weaken breathing and the ability to take up oxygen.

- Elevated VEGF-D levels can help confirm the diagnosis of LAM without needing a lung biopsy.
- LAM causes multiple air-filled holes, called cysts, in the lungs. Often these cysts can rupture and cause air to leak outside of the lung, leading to lung collapse
- There is a possibility that pregnancy may lead to progression of LAM, so consult your doctor if you are pregnant or considering pregnancy

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